Research Updates
in kidney and urologic health

National Kidney and Urologic Diseases Information Clearinghouse

SPRING 2004

National Institute of Diabetes and Digestive and Kidney Diseases

NATIONAL INSTITUTES OF HEALTH

NIDDK Establishes Central Repositories

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) is committed to sharing research data and biological specimens collected by its funded researchers. The value of these resources extends well beyond the scope and duration of the funded project.

To facilitate sharing of the samples and data collected in selected large clinical studies, the NIDDK established the Central NIDDK Repositories in July 2003. The Central Repositories will allow the broader research community to access the biosamples and data from many studies.

There are three Central Repositories:

1. **Biosample Repository** (administered by McKesson Bioservices Corp., Rockville, MD)—Receives biosamples collected in many different studies, stores the samples under optimal conditions, and distributes them to qualified investigators.

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2. **Genetics Repository** (administered by Rutgers, The State University of New Jersey, New Brunswick, NJ)—Receives blood samples collected in many different studies and processes them to create immortalized cell lines and DNA samples. In addition, the Genetics Repository also cryopreserves blood cells, extracts DNA from blood samples, stores samples of DNA under optimal conditions, and distributes DNA samples to qualified investigators.

3. **Data Repository** (administered by Research Triangle Institute, Research Triangle Park, NC)—Receives, archives, maintains, and distributes databases or parts of databases

REPOSITORIES, *continued on page 6*

Inside This Issue...

U.S. Department of Health and Human Services

NIH Changes Policy on Mentored Career Development Awards

Concurrent Support from Research Grant Now Allowed

In February 2004, the National Institutes of Health (NIH) implemented a policy change to allow recipients of mentored career development awards (K Awards) to hold concurrent support from their career award and a competing research grant when recognized as a principal investigator or subproject director. To be eligible, K Award recipients must be in the last 2 years of their support period. Recipients will be permitted to reduce the level of effort required for the career award and replace that effort with an NIH research grant or subproject as long as they remain in a mentored situation. This policy will permit candidates who are ready to apply for and receive NIH research support to continue to benefit from the period of protected time offered by the career development award.

The intent of the Career Development Program is to provide a final mentored period of support to facilitate the transition of the candidate to independence and to allow the candidate to accumulate the data and expertise needed to apply for an initial R01 grant.

NIH mentored career development mechanisms are designed to help recent graduates of doctoral programs in the biomedical and behavioral sciences prepare to be independent researchers. The Mentored Research Scientist Development Award (K01) provides support for an intensive, supervised career development experience in one of the biomedical, behavioral, or clinical sciences leading to research independence. To be eligible for a K01, the applicant must have a Ph.D. The goal of the NIDDK K01 program is to ensure a future cadre of well-trained scientists.

Applicants who obtained an M.D. are eligible for either a K08, if they are pursuing basic research, or a K23, if they are pursuing patient-oriented research. The K25 is a mentored quantitative research career development award that assists individuals with an advanced degree in quantitative research (physics, mathematics, chemistry, and so on) who wish to apply their skills to biomedical sciences.

The intent of the Career Development Program is to provide a final mentored period of support to facilitate the transition of the candidate to independence and to allow the candidate to accumulate the data and expertise needed to apply for a regular research grant.

In some cases, the former NIH policy delayed the period of transition to independence until the career award was completed or nearly completed. This policy often led to a hiatus in research support and an increased likelihood that career award recipients would not make the transition to independent research support. Some Institutes at the NIH discontinued mentored career awards as soon as a candidate received independent research funding. With this announcement, the NIH will no longer cut off a career award when the recipient receives an NIH research project grant or when the recipient is named as the director of a subproject on a multi-project NIH grant. This policy is consistent with the NIH Roadmap initiative in terms of promoting the career development of clinical researchers. This change in policy should facilitate the transition of all mentored career award recipients to independent NIH research support.

For competing research applications submitted by February 1, 2004, and beyond, mentored career award recipients in the last 2 years of career award support are encouraged to obtain funding from NIH either as principal investigator on a competing research grant award or cooperative agreement, or as project leader on a competing

multi-project award. Requested budgets for a competing research grant or a subproject on a multi-project grant should include appropriate amounts for the salary and associated costs for the career recipient's effort. At the time the research grant is awarded, the effort required on the career award may be reduced to no less than 50 percent and replaced by effort from the research award so that the total level of research commitment remains at 75 percent or more for the duration of the mentored career award. This change in policy applies to the following mentored career award mechanisms: K01, K07 (developmental), K08, K22, K23, and K25, as well as to the individuals mentored through institutional K12 awards.

More information about the requirements for concurrent funding can be found online at *http://grants2.nih.gov/grants/guide/notice-files/NOT-OD-04-007.html.*

For additional information concerning this change, contact

Walter T. Schaffer, Ph.D.
Acting Director, Office of Extramural Programs
NIH Research Training Officer
6705 Rockledge Drive, Room 3537
Bethesda, MD 20892–7922
Phone: (301) 435–2687
Email: ws11q@nih.gov

For information on NIDDK career and training programs, contact

Terry Rogers Bishop, Ph.D.
Director, Training and Careers Program
Division of Kidney, Urologic, and Hematologic Diseases
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Bethesda, MD 20892–5458
Phone: (301) 594–7717
Email: bishopt@extra.niddk.nih.gov ■

Recent Meetings

Urologic Complications in Diabetes

In December 2003, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), in partnership with the American Urological Association, convened an international group of clinical and basic researchers to discuss urologic complications of diabetes including bladder, sexual, and erectile dysfunction as well as urinary tract infections. The meeting included a series of short presentations on current understanding, knowledge gaps, and future directions for research on urologic complications among men and women with diabetes.

Oxalosis and Hyperoxaluria

In November, NIDDK sponsored a meeting on primary hyperoxaluria, a rare genetic disease that results from endogenous (primary) overproduction of oxalic acid. Research on the disease has elucidated the metabolic defects and molecular genetic basis for two forms of the disease and has led to improved diagnosis and treatment. However, more research is clearly needed to develop novel approaches for treatments and, eventually, cures. The goals of this meeting were to summarize knowledge that can be used to develop consensus algorithms for diagnosis and treatment, apply new science to influence the phenotypic expression, and promote participation in clinical and mutation databases.

Research Insights Into Interstitial Cystitis: A Basic and Clinical Symposium

At the end of October, NIDDK and the Interstitial Cystitis Association co-sponsored a symposium where potential treatments actively being researched were discussed as were potential markers to diagnose IC and new research that may ultimately reveal IC's causes. Topics included urothelial characterization and function, inflammation and signaling in the bladder, lower urinary tract neuroplasticity, detrusor function and regulation, and neuroimaging. ■

NIDDK Researchers to Explore Pathways on NIH Roadmap

In September 2003, Director of the National Institutes of Health (NIH) Elias A. Zerhouni, M.D., unveiled a series of far-reaching initiatives known collectively as the NIH Roadmap for Medical Research. The NIH Roadmap is an integrated vision to deepen our understanding of biology, stimulate interdisciplinary research teams, and reshape clinical research to accelerate medical discovery and improve people's health. Following this plan will lead to a more efficient and productive system of medical research.

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) will join all NIH institutes and centers in promoting three Roadmap themes:

- New Pathways to Discovery
- Research Teams of the Future
- Re-engineering the Clinical Research Enterprise

NIDDK will participate in all of these agency-wide programs designed to develop new technologies and foster new approaches to the puzzles of health and disease.

NIDDK encourages researchers to pursue the funding opportunities that will emerge as more NIH Roadmap programs are announced. NIH has already issued several requests for applications (RFAs) for programs that promote the NIH Roadmap themes. The programs described here demonstrate how NIH intends to keep pace with the health demands of the 21st century.

New Pathways to Discovery

Better instruments lead to better understanding of the many interconnected networks of molecules that make up our cells and tissues and regulate their interactions. Scientific tools developed in the past decade are providing many pieces of information that have yet to be fully understood. To make the most of the recent completion of the human genome sequence and many recent discoveries in molecular and cell biology, the research community needs increased access to technologies, databases, and other scientific resources that are more sensitive, more robust, and more easily adaptable to researchers' individual needs.

One of the first NIH-wide programs designated to support this Roadmap theme is Metabolomics Technology Development (RFA-RM-04-002), a program to encourage the development of highly innovative and sensitive tools for identifying and quantifying cellular metabolites and their fluxes at high anatomical, spatial, and temporal resolution. Originally proposed as an NIDDK initiative, the Metabolomics program will invite researchers from all medical disciplines and research fields. Although the issues of metabolism are most closely associated with diabetes and digestive diseases, the technologies developed under this initiative will play a major role in transferring capabilities to laboratories and research institutes that are investigating the underlying pathways involved in cellular homeostasis, perturbation, development, and aging. Metabolomics and other initiatives for New Pathways to Discovery will provide a solid scientific foundation for new strategies for diagnosing, treating, and preventing disease.

Research Teams of the Future

The scale and complexity of today's biomedical research problems increasingly demand that scientists move beyond the confines of their own disciplines and explore new organizational models for team science. For example, imaging research often requires radiologists, physicists, cell biologists, and computer programmers to work together on integrated teams. Many scientists will continue to pursue individual research projects; however, they will be encouraged to change the way they approach the scientific enterprise. NIH wants to stimulate new ways of combining skills and disciplines in both the physical and the biological sciences. The Director's Innovator Award will encourage investigators to take on creative, unexplored avenues of research that carry a relatively high potential for failure but also possess a greater chance for truly groundbreaking discoveries. In addition, novel partnerships, such as those between the public and private sectors, will be encouraged to accelerate the movement of scientific discoveries from the bench to the bedside.

As part of the Research Teams of the Future theme, the NIH has issued the RFA Exploratory Centers for Interdisciplinary Research (RFA-RM-04-004). This RFA invites applications for planning grants using the P20 (exploratory center) mechanism that will focus on developing new approaches to solving significant and complex biomedical problems, particularly those that have eluded more traditional approaches. These new approaches must hold the promise of leading to new research that improves human health.

These planning grants are expected to identify a biomedically relevant problem, evaluate why previous approaches have not worked, justify why the proposed interdisciplinary approach will work, identify the planning approach, and propose a timeline. The planning approach could include holding workshops or conducting feasibility studies, but these are only examples of possible planning approaches. Success is defined as combining aspects of individual disciplines to provide a new approach to solving a problem that could not have been achieved by an isolated laboratory. The planning grant should request 3 years of funding.

Re-engineering the Clinical Research Enterprise

Ideally, basic research discoveries are quickly transformed into drugs, treatments, or methods for prevention. Such translation lies at the very heart of NIH's mission. Although NIH historically has funded medical research that has helped to transform once acute and lethal diseases into more chronic ones, it has become clear to the scientific community that our country needs to recast its entire system of clinical research to remain as successful as in the past.

Over the years, clinical research that helps discover mechanisms of disease, prevention, diagnosis, or treatment has become more difficult to conduct. Yet the exciting discoveries we are currently making require us to conduct even more efficiently the complex clinical studies required to make rapid medical progress and to further inform our basic science efforts. This is undoubtedly the most challenging but critically important area identified through the NIH Roadmap process.

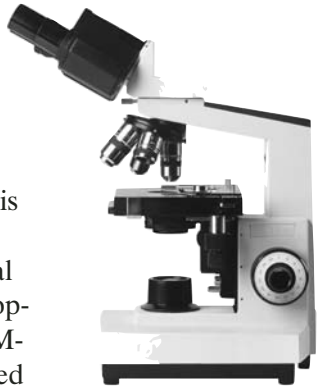
At the core of this vision is the need to develop new research partnerships with organized patient communities, community-based physicians, and academic researchers. This also includes the need to build better-integrated networks of academic centers linked to a qualified body of community-based physicians who care for sufficiently large groups of patients interested in working with researchers to

ROADMAP, *continued on page 6*

ROADMAP, *continued from page 5*

quickly develop and test new interventions. This vision will require new paradigms in how clinical research information is recorded, new standards for clinical research protocols, modern information technology platforms for research, new models of cooperation between NIH and patient advocates, and new strategies to re-energize our clinical research workforce.

Re-engineering the Clinical Research Enterprise is intended to address these pressing needs by promoting the better integration of existing clinical research networks, encouraging the development of technologies to improve the assessment of clinical outcomes, harmonizing regulatory processes, and enhancing training for clinical researchers. A major goal of this initiative is to more fully involve and empower the public in the research process.



One of the first NIH initiatives to promote this Roadmap theme is the Multidisciplinary Clinical Research Career Development Program (RFA-RM-04-006), which is designed to support the early career development of clinical researchers from a variety of disciplines engaged in all types of clinical research, including patient-oriented research,

ROADMAP, *continued on page 7*

REPOSITORIES, *continued from page 1*

from studies. In addition, the Data Repository analyzes stored data in response to inquiries, assists ongoing studies in preparing data for eventual archiving, coordinates cross-referencing between the three Central Repositories, and maintains the Central Repositories website.

NIDDK will designate studies to submit samples or data to the Central Repositories. Among the current repository holdings are plasma, serum, and DNA samples collected by NIDDK's Dialysis Access Consortium. Ongoing trials that will contribute samples and data to the repositories include the Polycystic Kidney Disease Treatment Network (HALT PKD), Chronic Renal Insufficiency Cohort Study (CRIC), Hemodialysis Study (HEMO), Folic Acid for Vascular Outcome Reduction in Transplantation (FAVORIT), Complementary and Alternative Medicine for Urological Symptoms (CAMUS).

All qualified investigators will be allowed access to the stored materials at the end of a pre-determined proprietary period, which will be mutually agreed upon by the study's steering committee and NIDDK. In general, this proprietary period will be no longer than 2 years from accrual of the last sample or patient data.

Sharing reinforces open scientific inquiry, encourages diversity of analysis and opinion, promotes new research, makes possible the testing of new or alternative hypotheses and methods of analysis, supports studies on data collection methods and measurement, facilitates the education of new researchers, enables the exploration of topics not envisioned by the initial investigators, and permits the creation of new datasets when data from multiple sources are combined.

Additional information about the NIDDK Central Repositories can be found online at *www.niddkrepository.org.* Inquiries should be sent to Rebekah S. Rasooly, Ph.D., Division of Kidney, Urologic, and Hematologic Diseases, NIDDK, (301) 594–6007, *repositories@extra.niddk.nih.gov.* ■

ROADMAP, *continued from page 6*

translational research, small- and large-scale clinical investigation and trials, and epidemiologic and natural history studies. These individuals would be expected to achieve excellence in their ability to design and oversee research in multidisciplinary team settings and have a high potential to become leaders of various fields of clinical research critical to the overall mission of NIH.

The program will train and foster the career development of individuals with doctoral-level professional degrees to become the next generation of clinical researchers who will perform clinical investigation in multidisciplinary, collaborative clinical research settings. Career development programs supported under this RFA must include a broad representation of clinical disciplines and professions (e.g., internal medicine, surgery, pediatrics, obstetrics/gynecology, dentistry, pharmacy, statistics, nursing, psychology) and their various specialties and sub-specialties. Programs must include a structured core didactic component and a practical training component in various aspects of the design, conduct, and analysis of clinical research. Individuals should be trained in team research settings and will be known as NIH Clinical Research Scholars (CR Scholars).

Taken together, the components of these initiatives are part of a well-thought-out national portfolio of research to stimulate innovation and collaboration. NIDDK is committed to supporting those goals. More information about the NIH Roadmap can be found at *http://nihroadmap.nih.gov.* Further information about the NIH can be found at its website: *www.nih.gov.* ■

Take In NIH Conferences Without Leaving Your Desk

Can't fly to the NIH campus to attend a conference or workshop that looks particularly interesting? You can still get all the information you need by logging on to *www.videocast.nih.gov.* A complete schedule of current and future events, plus an archive of past events, is available on this website. Most of the conferences are available to anyone who accesses the website.

A few of the available presentations that may be of interest to readers of *Research Updates in Kidney and Urologic Health* are

- **Altruistic Kidney Donation**
  Thursday, March 4, 2004
- **NIH Roadmap for Medical Research Briefing by NIH Director**
  Friday, February 27, 2004

The Center for Information Technology (CIT) makes special NIH events, seminars, and lectures available to viewers on the NIH network and the Internet from the VideoCast website. VideoCasting is the method of electronically streaming digitally encoded video and audio data from a server to a client. Streaming video is best viewed with a high-speed network connection and high color or better color setting. At a minimum, your computer will need VGA graphics with at least 256 colors, a sound card with speakers or headphones, and a network connection or high-speed modem. VideoCasts can be viewed using RealOne or RealPlayer software, which can be downloaded and installed for free from Real Networks. ■

NIDDK Supports Epidemiology of Interstitial Cystitis

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has issued a request for applications (RFA) to support investigation of the epidemiology of interstitial cystitis and painful bladder syndrome (IC/PBS) in response to recommendations from the Interstitial Cystitis (IC) Epidemiology Task Force. The group—the IC Executive Committee, ad hoc participants, and National Institutes of Health (NIH) staff—met in Bethesda, MD, last October to review current investigations of IC and to plan new epidemiology investigations. The request for applications is available online at *http://grants.nih.gov/grants/guide/rfa-files/RFA-DK-04-009.html.*

The objectives of the research program described in this RFA are to

- develop a population sampling strategy to survey the prevalence of people with symptoms of IC/PBS
- develop diagnostic categories and methods for assessing the severity of IC/PBS symptoms
- develop questionnaires to assess IC/PBS using both current examples of symptom assessment and advice of IC/PBS experts
- conduct well-designed, population-based studies that will estimate the prevalence of people with IC/PBS symptoms and determine the characteristics of that population
- provide for clinical evaluations of a subset of symptomatic individuals and control subjects by clinicians with demonstrated IC expertise
- assess quality of life, severity of pain, and the impact of pain issues
- determine the socioeconomic impact of IC/PBS

Points of Consensus

The task force reached consensus on several points that should inform the effort to standardize the epidemiological study of IC.

IC is a symptomatic diagnosis based on the presence of three key symptoms, pain, urgency, and frequency, as well as the exclusion of a few other conditions that cause the same symptoms.

- Pain is the most consistent and disabling symptom for IC patients. Some will not use the term pain, but will instead describe a sense of pressure or discomfort. Typically, but not always, the pain is worse when the bladder is filling and is relieved as the bladder empties.
- Urgency in IC patients differs from that experienced by patients with urinary incontinence. In IC patients, the urgency is driven by pain; in patients with incontinence, it is driven by their fear of losing control.
- Not enough information is available on normal variability of urinary frequency to establish a number that can help diagnose IC.

NIDDK criteria for IC were developed to select a set of patients for clinical trials. Many patients who experienced clinicians would agree have IC do not meet these criteria, making the criteria too restrictive for epidemiologic studies. The criteria used by experienced clinicians need to be standardized for use in epidemiologic studies.

Even asking subjects whether they have ever been diagnosed with IC is not useful because they frequently confuse the term "interstitial cystitis" with "acute bacterial cystitis."

Recommendations

The task force issued the following recommendations to address the methodological issues researchers will face in this effort.

1. Use a population-based sampling strategy to identify people who have symptoms of IC/BPS. An example of this type of strategy is the one used by the Chronic Fatigue Syndrome Research Program of the Centers for Disease Control and Prevention.
2. Perform more intensive evaluation on a sample of symptomatic subjects and on control subjects.
3. Draw a sample for intensive study from a region in the United States near one or more clinical evaluation sites.
4. Consider a national strategy for telephone surveys, if cost permits.
5. Include people with early symptoms of the illness in the study. Enrollment targets should ensure an adequate number of short-term patients.
6. Limit the survey to persons with bladder symptoms, eliminating people who have vulvodynia or chronic pelvic pain.
7. Perform prospective studies to identify the risk factors for developing IC/PBS.
8. Perform a longitudinal study of symptomatic subjects and controls as resources permit. Although the case literature and the Interstitial Cystitis Database provide some valuable information on the natural history of established IC, the natural history of early symptoms is unclear.
9. Perform studies to validate the sensitivity and specificity of antiproliferative factor for diagnosis of IC. Assess the value of measuring antiproliferative factor in a sub-group of symptomatic persons to predict progression of IC and to monitor their responses to therapy.
10. Collect biosamples from subjects and perform microarray and proteomics analyses to develop other markers of IC that might contribute to an understanding of disease pathogenesis. Samples suitable for such studies should be stored in a repository, and access should be arranged for qualified investigators. ■

New Publications From NKUDIC

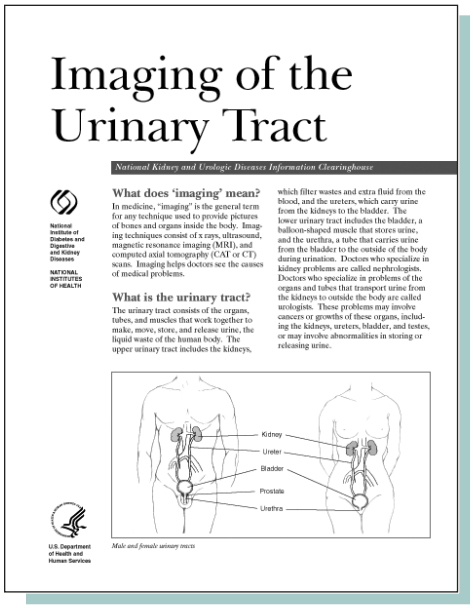
The National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) is pleased to announce two new fact sheets on urologic problems and a new series of fact sheets on kidney disease in children.

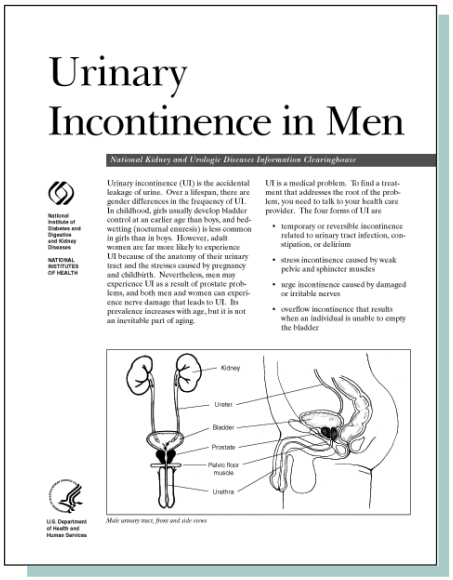
Urinary Incontinence in Men

Although urinary incontinence (UI) is more common in women, nerve problems, prostate enlargement, and treatments for prostate cancer can all create continence issues for men. This fact sheet for patients discusses the causes of UI in men, how it is diagnosed, and the range of treatments available.

Imaging of the Urinary Tract

Many urologic problems require medical imaging for diagnosis or evaluation. This fact sheet explains the range of imaging technologies used to evaluate the urinary tract, including ultrasound, conventional radiology, magnetic resonance imaging, and computed tomography. The fact sheet instructs patients on how to prepare for an exam and what to expect.





Kidney Failure in Children Series

NKUDIC has released a series of new publications on kidney disease in children. Written for parents, the series includes general fact sheets on the causes of and treatment methods for kidney failure as well as fact sheets that focus on specific complications such as growth failure and psychosocial problems. Members of the American Society of Pediatric Nephrology provided scientific and editorial review for each publication.

- ***Overview of Kidney Disease in Children*** describes the major causes of kidney disease and kidney failure in children, lists risk factors for kidney disease, explains the difference between acute kidney disease and chronic kidney disease, and introduces specific conditions such as hemolytic uremic syndrome, nephrotic syndrome, birth anomalies, urinary obstruction, hereditary diseases, and glomerular diseases.
- ***Treatment Methods for Kidney Failure in Children*** covers transplantation, peritoneal dialysis, and hemodialysis. Although these are the same options available to adults, the priorities for treating children are different. Transplantation provides the best opportunity for a child to

New Publications, *continued on page 12*

New in CHID

CHID online

Each quarter, the National Kidney and Urologic Diseases Information Clearinghouse adds about 150 items to the kidney and urologic diseases (KU) subfile of the Combined Health Information Database (CHID). This database contains abstracts and ordering information for professional resources and patient education materials—such as books, pamphlets, videos, journal articles, and manuals—dealing with a variety of kidney and urologic topics. Recently, the KU subfile has begun to include resources available online. *CHID Online* can be accessed at *www.chid.nih.gov* on the Internet. Among recent additions to the KU subfile are these materials on kidney disease and treatments for pain in interstitial cystitis.

Help Your Family Prevent Kidney Failure

The brochure from the National Kidney Disease Education Program (NKDEP) emphasizes that kidney disease runs in families and that early detection of kidney disease is important. The brochure features key messages about kidney disease on a detachable postcard that patients mail to their family members.

Available from National Kidney Disease Education Program, 6903 Rockledge Drive, Suite 540, Bethesda, MD 20817. This brochure is also available on the NKDEP website at *www.nkdep.nih.gov*.

The Kidney Learning System Catalog

The National Kidney Foundation (NKF) is a principal authority in chronic kidney disease (CKD). In 2003, the NKF launched its Kidney Learning System (KLS), which is focused on education, early patient identification, prevention, and clinical applications that improve outcomes. This program emphasizes that the information people need to know about CKD differs depending on the stage of the disease. Therefore, all KLS materials are categorized by CKD stages along the continuum of care. This catalog lists the materials available through the KLS program. Materials are listed by category—public education, at-risk patients, and patient and professional materials in stages 1 through 5—as well as transplant level. Each item in the catalog is briefly described and

cost information is provided. The catalog is illustrated with photographs of some of the covers of the materials as well as quotations from the materials. The catalog also includes a brief description of resource extras, other programs and solutions of the KLS, and a brief description of the goals and activities of the

CHID, *continued on page 12*

CHID, *continued from page 11*

NKF. An order form for materials is also provided.

Available from National Kidney Foundation, Inc. Medical Department, 30 East 33rd Street, New York, NY 10016. 1–800–622–9010. Fax: (212) 689–9261. Email: info@kidney.org. website: *www.kidney.org.*

Interstitial Cystitis Association Treatment Options

The Interstitial Cystitis Association (ICA) website (www.ichelp.org) offers a number of resources for patients and physicians. The ICA Treatment Options section (www.ichelp.org/TreatmentAndSelfHelp/TreatmentGuidelines.html) is designed to help physicians and patients develop a step-by-step treatment plan. The ICA Treatment Guidelines page details the symptoms of interstitial cystitis (IC) and diagnostic procedures. Symptoms vary from patient to patient, so each patient requires an individual treatment plan. Non-invasive techniques such as diet modification and self-help may be used in combination with more aggressive treatment modalities. The Treatment Guidelines page lists oral medications and bladder instillations that may be used to relieve the symptoms of IC. Clinical trials are testing additional treatment options. An IC Terminology Guide provides a comprehensive glossary of medical and pharmaceutical terms.

Patients can contact the ICA by writing to 110 North Washington Street, Suite 340, Rockville, MD 20850. The phone number is 1–800–HELP–ICA or (301) 610–5300. Email: icamail@ichelp.org. ■

New Publications, *continued from page 10*

grow and develop normally. Peritoneal dialysis and hemodialysis can keep a child healthy until a donated kidney becomes available.

- ***Childhood Nephrotic Syndrome*** describes the symptoms of and treatments for nephrotic syndrome in children and includes a discussion of minimal change disease and steroid-resistant nephrotic syndrome.
- ***Hemolytic Uremic Syndrome*** explains how HUS, the most common cause of acute renal failure in children, develops after *E. coli* infection in the digestive tract and describes the treatments available.
- ***Growth Failure in Children With Kidney Disease*** explains how kidney disease can interrupt a child's physical development, cause bone deformities, and prevent the child from reaching full adult stature; describes the therapies available to minimize those problems.
- ***School and Family Problems of Children With Kidney Disease*** describes the psychosocial problems that can accompany kidney disease, including issues of fitting in at school, financial demands of treatment, and family stresses that can result; covers the role of the social worker and other members of the health care team available to help families.

Single copies of each publication are available free of charge and in packages of 25 for $5. To order these fact sheets, see the order form in this newsletter, call NKUDIC at 1–800–891–5390, or use our online catalog at *www.catalog.niddk.nih.gov.* NKUDIC publications are also available at *www.kidney.niddk.nih.gov* on the Internet. Just click on "Kidney and Urologic Diseases" or on "A to Z List of Kidney and Urologic Diseases" to see a list of titles.

Since NIDDK's health information materials are a public service and are not copyrighted, health care professionals are encouraged to duplicate these publications as handouts for their patients or as an insert for office or association newsletters. ■

Upcoming Conferences and Workshops

Organ Innervation: Development, Disease, and Repair

Contact: Aimee Benton, the Hill Group
abenton@thehillgroup.com
Date: April 15–16, 2004

Organ dysfunction as a consequence of neural defects or injury is a common and debilitating problem. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) is organizing this workshop on organ innervation to review current knowledge in this field, identify impediments to research, and map out new avenues for research. An international group of investigators will convene to discuss innervation during development and disease progression and following injury. Developmental mechanisms underlying neural crest fate specification and migration to specific organs as well as factors that guide these processes and regulate neural survival will be considered. Mechanisms of neural injury, autonomic plasticity, and repair will also be emphasized.

Protein Misfolding and Misprocessing in Disease

Contact: Aimee Benton, the Hill Group
abenton@thehillgroup.com
Date: May 4–5, 2004

Extensive new research on protein folding and misfolding, especially within the endoplasmic reticulum, is providing fascinating insights into the mechanisms by which disease-associated proteins aggregate and injure cells. This workshop will focus on both basic science and clinical issues. Speakers will discuss new concepts for therapeutics, including the use of small molecules and chaperones to prevent protein misfolding or aggregation, to enhance the removal of toxic protein aggregates, or to block the cellular response to the defective protein. Plenary talks, selected short talks, and a poster session will provide a forum for interactions among both basic and clinical scientists, as well as established and new investigators in the field.

First NIH Office of Rare Diseases Conference on Cystinosis: Past, Present, and Future

Contact: Marva Moxey-Mims, M.D.
moxey-mimsm@extra.niddk.nih.gov
Date: May 12–13, 2004

A working group of 25 experts inside and outside the National Institutes of Health, and inside and outside the field of cystinosis, has been assembled to review the current knowledge of cystinosis and to develop ideas about the future basic and clinical research in this disease. Topics discussed will include cystine-depleting therapy, renal disease, renal replacement therapy, nonrenal complications, basic research, and future strategies. The Cystinosis Research Network and Cystinosis Foundation are co-sponsors. Representatives of family groups will attend the conference.

Preparing for a Career in Clinical Research in Kidney and Urologic Diseases

Contact: Aimee Benton, the Hill Group
abenton@thehillgroup.com
Date: July 9–10, 2004

Highly trained clinical researchers are needed to capitalize on the many profound developments and discoveries in the basic sciences and to translate them to clinical settings. Unfortunately, formal training in clinical research is often fragmented, producing a workforce that is unprepared for such tasks. The Division of Kidney, Urologic, and Hematologic Diseases of NIDDK is sponsoring a 2-day opportunity to learn the skills needed for a successful clinical research career and the skills to effectively compete for research funding. The training program will include state-of-the-art lectures, mentored training sessions on clinical research and study design for kidney and urologic diseases, grant writing, and a mock study section. The goal of the program is to provide a broader knowledge base for participants, so that they compete more effectively for research funding. ■

NKUDIC Publications List

Patient Education Fact Sheets

Single copies free. Packages of 25, $5 each.

KU–145 Amyloidosis and Kidney Disease
KU–146 Anemia in Kidney Disease and Dialysis
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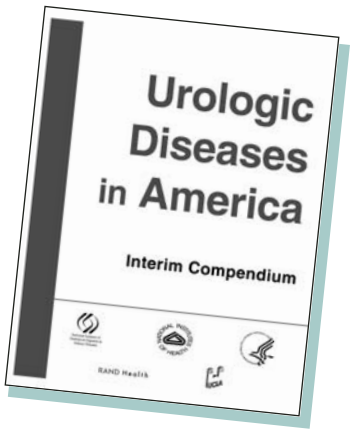

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